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Schmieding Conference on Elder Homecare
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REPORT OF FINDINGS

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STATE AND EMPLOYMENT BARRIERS OBSTRUCTING IN-HOME ELDERCARE

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SOLUTIONS FOR KEEPING ELDERS AT HOME FOR LIFE

TESTIMONY OF PAMELA D. BATAILLON TO THE POLICY COMMITTEE OF THE WHITE HOUSE CONFERENCE ON AGING

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SUMMARY OF FINDINGS

Background

- Care giving has been a universal experience in society; historically, largely the role of family and of relatively short tenure.
- Family members are often dispersed over a wide geographic area. Women, the traditional family caregivers of the past, now comprise nearly 50% of the labor force, and men comprise 44% of the care giving population.
- Today, the majority of people die from consequences of a chronic condition. Care giving situations span years or even decades.
- The growing movement away from institutionalization to community living firmly establishes care giving as an integral aspect of the health/long term care system.
- More than half of caregivers under the age of 65 are employed outside the home.

Overarching Issues

- We have a language barrier in the field. In a recent Milbank Quarterly, Robyn I. Stone explained that **"**long-term care is a concept that is difficult to get one's arms around, and the definition is increasingly less clear as the characteristics of and delivery settings for primary, acute and long-term care become harder to differentiate." Indeed, since most elders with long-term care needs live at home, care is further differentiated between home health care, which includes some level of skilled nursing and perhaps supervised supportive care, and care/services in the home, which typically includes personal care services such as hygiene and dressing and homemaker/chore services such as meal preparation and laundry.
- The "medical model" often dominates discussion of long-term care and, just as with the language barrier, confounds the issue. Long-term care is not about diagnosing and treating disease; it is a combination of social supports and some formal medical care. Other models are needed when the focus must be on how an individual functions on a daily basis and when evaluating self-care abilities. Such models must recognize the interconnectedness of housing, self-care, social supports and health care. Concerns for safety and proper care in the provision of in-home care are valid, to be sure, but an overly regulated and medicalized model hampers our ability to see the whole picture clearly, and thus to plan and provide needed supports.
- Long-term care is not on the radar. However we conceive of it or refer to it, long term care does not have the attention of opinion leaders in health policy. The 2004 Commonwealth Fund Health Care Opinion Leaders Survey, for example, suggests that among more than 300 such opinion leaders and innovators in health care delivery and finance, long term care is not a health policy priority for Congress over the next five years.
- Fragmentation barriers abound.
    - Information about home and community based services is diffuse.

- There is fragmented and inadequate care planning, communication, and service coordination among providers.
- Supports and safeguards for those seeking to independently employ caregivers are nonexistent or inadequate. Seniors and their families are generally ill-prepared to become full service Human Resource specialists in assuring screening, training, and oversight of unlicensed caregivers in such arrangements. Rarely is there any supervision or oversight; sometimes there is contractual or de facto supervision by a home health agency. The latter case, that in which a home health agency is providing skilled and perhaps some supportive care, is fraught with liability issues.
- Waiting lists and limited flexibility in scheduling, if services can be found, are quite common.
- Many seniors are reluctant to access caregiver services for a variety of reasons, one of which is the belief that Medicare will take care of all long-term care needs.

<u>Barriers at the State Level</u>

Common complaints from providers include:

- Insufficient funds to pay for needed services.
- State focus on long-term care is narrowly defined as Medicaid or dually eligible beneficiaries.
- Lack of available and affordable respite and emergency dependent care services when families need a break or become unavailable for care giving.
- Overly restrictive lists of activities that are permitted to be performed by each type of worker: homemaker, companion/sitter, personal care aide, home health aide.
- Fragmented and non-comprehensive assessment and monitoring of individual elder needs and plans of care.
- Inadequate resources for education, preventive services such as nutrition and exercise.
- Inadequate services such as chore/handyman, telephone reassurance and companionship, and transportation services --any one of which might make the difference for a senior seeking to remaining independent in his or her own home.
- Inadequate and episodic services and funding for home improvement and adaptive equipment. If available at all, it is often because of local charity efforts.
- Lack of information networks to allow providers to share information toward better care planning.
- Lack of available and appropriate community based placements for individuals with mental illness, and in many communities, for those with dementia.
- A need for more training of medical and home health community regarding care of Alzheimer's and dementia patients in the home.

More financial resources are needed--a troublesome recommendation for states in the current economic times. However, other supports are needed as well, and the state has important roles to fulfill:

- States must envision a bigger picture so that multifaceted strategies are developed which allow seniors and their caregivers to find and access the most appropriate and coordinated services which meet their needs and preferences.
- Long term care financing cannot be limited to Medicaid; nor can it be shared with private foundations, so often looked to for assistance in complex social problems. And it is a rare individual or family that can pay for long term care with cash out-of-pocket.
- Partnerships such as those with the insurance industry must be formed. As experience in underwriting long term risks and managing claims increases, the willingness of insurers to pay for long term care will increase. However, this will take time. The report of the Robert Wood Johnson Foundation's Program to Promote Long Term Care Insurance for the Elderly cautions that it is important to bear in mind the general reluctance of Americans to purchase insurance to cover future risk. A great deal of education will be needed.
- Statewide community needs assessment and data collection systems are needed that accurately reflect the needs of elders and of community capacity.
- There must be a commitment of funds to encourage planning at the community level, experimentation with innovative models, and a structure for communication and collaboration among the stakeholders.

- Legislative and regulatory environments must be created which assure safety and which protect seniors from fraud and abuse while at the same time supporting innovation and flexibility
    - Issues rising from the language barrier and the medicalization of care must be taken into consideration as laws and regulations are written. For example, the definition of home health and personal care can either prohibit or allow private agencies to provide long-term chronic care on a fee basis to elders. State laws govern who can administer medications.
    - Unlike the regulation of home health care and its largely 'skilled' providers, which is generally consistent from state to state, the regulation of personal caregivers varies widely. While federal regulations should continue to allow state determination in this arena, development of a model approach to training and oversight of such caregivers would be valuable. A model approach may include recommended language for state legislation and regulations and include such issues as: guidelines for determining whether new legislation is needed and whether/which providers should be licensed or certified; information system improvements for improved communication and care planning; and a design for oversight and quality assurance.

<u>Barriers in the Employment Environment</u>

- There is a large and growing shortage of all types of trained healthcare workers, including long term caregivers.
    - Nationwide, we are experiencing a shortage of high quality direct care workers, 90% of whom are women, aged 22 to 45- an age group that will decline in the coming decade.
    - Hourly wages for home health aides average between $6 and $8.50 an hour. Since many aides are offered only part-time work, workers are forced to juggle jobs among two or more employers. Annual incomes range from $7,000 to $12, 600, placing the typical long-term caregiver below the poverty line.
    - Health insurance is rarely offered; premiums are often unaffordable.
    - Caregivers working as independent providers hired by individual seniors have little recourse to Fair Labor Standards Act (FLSA) protections.
- Nearly one in every four households cares for an older family member, and nearly two thirds of the family caregivers are employed.
    - Early in 2003, the Pew Research Center found that 44% of Americans are worried about having to care for an aging parent or relative. Within corporations that percentage is higher: 54% of working Americans expects to assume elder care responsibilities during the next three to five years.
    - Caring for an older relative consumes an average of 12 to 13.5 hours each week, or 2 to 10 hours a day. Most caregivers will have these responsibilities for more than 6-1/2 years.
    - Whatever the employed caregiver's role, he or she must balance the responsibilities of serving their elders with the demands of job and career.
    - Employees caring for older family members take time from work to deal with care issues, pass up promotion and training opportunities, reduce contributions to their own retirement savings, and sometimes give up work entirely and retire early. The stress of care giving is linked to significantly higher rates of physical and mental health problems.
    - The challenges these working families face represent a very high cost to the business bottom line. Because of this understanding and to reduce these costs, American corporations have been investing in policies and programs to support employees with elder care responsibilities for over 15 years.
    - There are many areas in which employers can not only lessen the burdens that care giving places on their employees, but can also decrease absenteeism and increase employee loyalty and retention. Investments to support working families with elder care responsibilities have consistently shown an increase in workforce retention, productivity, and loyalty.
    - Businesses also know that significant new action is needed because of the growing magnitude of elder care. New public policies and public-private partnerships are required to support family care giving and to optimize future workforce development:

- Flexibility in working hours and/or ability to use sick leave for caring for family members.
- Financial assistance and tax breaks to help with costs for respite care, home modifications, medical supplies, equipment, and medicines.
- Modification of IRS definitions of dependent elder for Dependent Care Spending Accounts. Current IRS definitions of what constitute a dependent elder are too limited and prevent most families from being able to tax-defer expenses associated with elder care in the same way as they are able for child care expenses.
- Availability of affordable long-term care insurance to cover the catastrophic costs of nursing home care or in-home services.

Summary
It is apparent that just as it takes a village to raise a child, it takes a village to care for our elders, for the world is dramatically different than it was a century ago, when we didn't live as long and our family lived close by. American elderly value their independence and are concerned with self-reliance and dignity. But they and their families and their caregivers need help. Issues of government economic assistance for the elderly are becoming of paramount importance. Employers have become more involved with the eldercare issue. The insurance industry has responded to the need. Many other issues, such as how we conceive of long term care, must be worked out. The White House Conference on Aging is in a key position to put long term care 'on the radar', to foster broad discussion on the value of and the solutions for providing services to help our seniors live as independently as possible in their homes and their communities.

I thank the Schmieding Center and the International Longevity Center for hosting this important focus on in-home care giving and am happy to answer any questions.